

My Life

Information and advice for patients

Supportive and Palliative care

My Life

This booklet has been developed for you to keep and use to support you at this time. It supports the Gold Standards Framework and the Supportive Care Plan.

How can I use this booklet?

You can use this booklet to record:

- Your personal contact information and medical
- Your medical history
- Services involved in your care
- Your advance care plan wishes
- Advice given to you following a consultation or healthcare professional visit
- A personal diary

It also includes information on national and local support organisations.

How can healthcare staff use this booklet?

This booklet will also be used by healthcare staff when they visit you at home, they will discuss with you any information you include in it. Please show this booklet to them if they do not ask for it.

You can also take it with you to any appointments you have at the hospital, hospice or healthcare centre.

The doctors and nurses involved in your care will still continue to use your medical/healthcare records and nursing care plan. This booklet will complement these, not replace it.

What is the Gold Standards Framework?

The Gold Standards Framework is a national programme to help healthcare staff provide a 'Gold Standard' of care for patients with palliative care needs. Their goals for you are that:

- your physical symptoms are anticipated and reduced where possible.
- you feel you are able to discuss your wishes and choices around your care.
- you feel supported and informed.
- your family/carer feel supported and informed.
- staff involved in your care work effectively, communicate and provide the best possible standard of care and support.

The Gold Standards Framework is used by all healthcare staff in Sandwell. Some local care homes also use the framework which has a specially tailored 'Care Homes Programme'.

Further information on the National Gold Standards Framework can be found on the website: www.goldstandardsframework.org.uk

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What is the Supportive Care Plan?

This is a patient held plan that is used by healthcare staff when assessing you and planning your care for you in hospital and at home.

The aim of the plan is to enable supportive care for patients with a life limiting illness. The focus of care is on comfort and quality of life. It will complement the care plan or treatment plan that you may have with your community nurse or GP.

This is your personal booklet, please keep it safe.

My Personal Information

My Name:
My Address:
Tel No:
Date of Birth:
My Next of Kin:
Relationship:
Address:
Tel No:
Other Family/Carer Contact:
Relationship:
Tel No:

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My Diagnosis:
My Relevant Medical History:
My Diagnosis:
Useful Information:
My Allergies:
What allergy reaction do I have?

Who is involved in my care?

Role:	Name:	Contact Details:
GP:		
Consultant:		
District Nurse:		
Hospice at Home: (Community Palliative Care Team)		
Hospital Palliative Care/ Macmillan Nurse:		

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Community matron:		
Specialist Nurse:		
Social Worker:		
Out of Hours Medical		
Service:		

Please ask your Health Care Professional for help if you are unsure of these details

Advance Care Planning – Advance Statement

This page is for you to express your wishes and priorities about any future care you receive. This is an 'advance statement' of your wishes and will be used as a guide to inform us when planning your care. (This is different from an 'advance decision', which is a legally binding document to refuse specific treatments – see below.) This template has been adapted from the 'Thinking Ahead' document developed by the national Gold Standard Framework Centre.

What is important to me at this time in my life?
(For example: What makes me happy – being at home or having family near)

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What elements of care are important to me?
(For example: What would I like to happen and what would I worry about)

My Preferred Place of Care – (If my condition deteriorates, where would I most like to be cared for)

1st choice

2nd choice

Comments:

Signed:

Date:

Useful Information

Advance Decision to refuse treatment

The Mental Capacity Act (2005) gives adults in England and Wales a statutory right to refuse treatment, through an 'advance decision'. An advance decision to refuse treatment lets you state what forms of treatment you do not wish to have in specific circumstances, if you lose capacity to make a decision in the future.

An advance decision to refuse treatment:

- Must state precisely what treatment is to be refused – a statement giving a general desire not to be treated is not enough.
- May set out the circumstances when the refusal should apply – it is helpful to include as much detail as possible.
- Will only apply at a time when the person lacks capacity to consent to or refuse the specific treatment. Specific rules apply to life sustaining treatment.

Further information on 'Advanced Decision to refuse Treatment' can be found on the website: www.endoflifecareforadults.nhs.uk/publications/pubadrtguide

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If you do not have access to the internet, please speak to a health care professional for more information.

<p>I have an 'Advance Decision to Refuse Treatment'? If yes, please give details of where this is kept and who has a copy:</p>	<p>Yes/No</p>
<p>I have a 'Do Not Attempt Resuscitation' decision? If yes give details of where this form is kept:</p>	<p>Yes/No</p>

Lasting Power of Attorney Information

The Mental Capacity Act (2005) allows people aged 18 and over to choose and appoint someone to make their health welfare and/or financial decisions if in the future they lack capacity to make these decisions for themselves. This person is called an attorney and is appointed by a formal document called a Lasting Power of Attorney (LPA). There are two different types of LPA:

- A personal welfare LPA is for decisions about both health and personal welfare, such as where to live, day to day care or having medical treatment.
- A property and affairs LPA is for decisions about finances, such as selling the house or managing their bank account.

Before an LPA can be used, it must be registered with the Office of the Public Guardian. Information on the LPA and the Office of the Public Guardian can be found at www.direct.gov.uk and there is a cost involved.

<p>I have a Lasting Power of Attorney for Health: If yes, give details:</p>	<p>Yes/No</p>
<p>I have a Lasting Power of Attorney for Welfare? If yes, give details:</p>	<p>Yes/No</p>

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Contact details

If you do not have access to the internet, please remember that most local libraries have computers available for public use. There may be a small charge involved for use of the internet. You can also speak to staff involved in your care for more information.

Macmillan Cancer Support website and helpline

Website: www.macmillan.org.uk

Tel: 0808 808 0000 (interpretation service available)

Other information on cancer

Information on different cancers

www.cancerresearchuk.org/cancer-help

Pan Birmingham cancer Network website:

Website: www.birminghamcancer.nhs.uk

Tel: 0121 627 2494

Information on non-cancer conditions

British Heart Foundation – information on Heart Failure

Website: www.bhf.org.uk

Tel: 0300 330 3322

British Lung Foundation – information on Lung Conditions

Website: www.lunguk.org

Tel: 0300 003 0555

Motor neurone Disease Association

Website: www.mndassociation.org

Tel: 01604 250 505

Parkinson's Disease Society

Website: www.parkinsons.org.uk

Tel: 0808 800 0303

Multiple Sclerosis Society

Website: www.mssociety.org.uk

Tel: 0808 800 8000

Alzheimer's Society – information on dementia

Website: www.alzheimers.org.uk

Tel: 0300 222 1122

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The Stroke Association

Website: www.stroke.org.uk

Tel: 0300 303 3100

Other information for Patients

Health Talk Online – patient experiences in relation to different conditions

www.healthtalkonline.org

Marie Curie Cancer Care

Website: www.mariecurie.org.uk

Tel: 0800 716 146

Age UK

Website: www.ageuk.org.uk

Tel: 0800 169 6565

Benefits Enquiry Line

Website: www.dwp.gov.uk

Tel: 0800 882200 (free to call from mobile)

Public Services Information

Website: www.direct.gov.uk

Sandwell (Smethwick) Citizens Advice Bureau.

Tel: 0121 552 2022, Monday – Friday, 2pm – 4pm

Tel: 0844 477 1010

<http://www.adviceguide.org.uk>

NHS local website

www.nhslocal.nhs.uk

Information for Carers

Carers UK

Website: www.carersuk.org

Tel: 0808 808 7777

Omega – care for life

Website: www.omega.uk.net

Tel: 0845 259 3163

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Sandwell Crossroads

Email: info@sandwellcrossroads.org

Crossroads Carer Scheme – Birmingham and Solihull

www.xroadsbham.org.uk

Bridges Support Service

Murray Hall Community Trust

Address: SGS House, John Lane, Oldbury, West Midlands, B69 3HX

Tel: 0121 612 2939

Email: bridges.support@nhs.net

Bereavement Services

For further information about bereavement services please ask your District Nurse or Community Palliative Care Nurse for our 'Bereavement Directory'.

Useful contacts (for you to add):

My Personal Diary/Notes

You may find this section useful to record how your treatment or medication is affecting you.

Date:	Personal Notes:

